

The ethics of space in clinical practice

Priscilla Alderson BA PhD Professor of Childhood Studies,
Social Science Research Unit, Institute of Education, University of London,

The ethics of space in clinical practice.

Abstract

The views of parents and staff about physical and symbolic space and its effects on ethical clinical practice are reported. Researchers observed four intensive care neonatal units in southern England, and interviewed 40 senior staff and the parents of 80 babies. The adults' concerns include: how space affects the sharing of information and responsibility for the babies; respect and welcoming policies; access, freedom of movement and accessibility of staff; family friendly space and privacy; aesthetic values and 'baby-led' space. The paper concludes that abstract principles of respect for autonomy, and attitudes towards the baby's biological and personal space take on practical embodied meanings in clinical spaces and practices. NICU design and aesthetics convey powerful ethical messages of welcome or exclusion that endorse or undermine partnerships between staff and parents. Helping premature and impaired babies to reach their space at the centre of their family involves sensitive management.

Key words

neonatal intensive care, informing and supporting parents, family centred care, babies' rights, decision making

INTRODUCTION

This paper draws on findings from a social research project,¹ in four neonatal intensive care units (NICUs) in southern England, 2002-2004. The project examined how staff and parents shared information about the babies, and responsibility for their care. This is a discussion paper rather than a research report. Over 18 months, three researchers (PA, JH, MK) observed daily practice in four NICUs. The study was unusual in that, besides holding tape-recorded semi-structured interviews with 40 NICU staff, the researchers also interviewed the mothers of 80 babies and 16 of the fathers in the NICU while their babies were being treated, as well as later at home. A second unusual feature is that parents were asked about their thinking and views and not mainly about their needs and emotions, which tend to be emphasised in more psychometric research. Like the staff, parents were treated primarily as rational reliable interviewees.

One aim of the study was to discover how parents and staff perceived and experienced the new approaches to more detailed sharing of complex and distressing information. Recent medico-legal-ethical guidelines emphasise that practitioners should give parents detailed information, and request their consent to all procedures except in emergencies.^{2 3 4 5 6 7} Significantly, the new guidance followed inquiries about the clinical treatment of babies and

young children,^{8 9} which suggests heightened ethical concerns about this most vulnerable group. While investigating the views of parents and staff about which types of care they found most beneficial, the study was not designed simply to compare the units. This was not quantitative research to measure performance, but qualitative research to examine how various policies and practices were adopted and experienced. Cross-unit comparisons are questionable if they rely on reported satisfaction rates of parents and staff who assume that practices in their own unit are inevitable and who are unaware of different standards and possibilities in other NICU. The observations, informal discussions with adults in the NICU and the interviews all provided many responses that are being reported in a series of papers.¹ A major concern was the physical environment or space of the NICU, and this paper reviews the themes that were raised relating to space and their practical and symbolic implications for clinical policy, practice and ethics. The themes include respect and family-friendly space, welcoming policies, access and freedom of movement, privacy within a public space, aesthetic values and 'baby-led' space. Although the ethics of space is analysed in this paper in relation to neonatal care, many of the examples apply in other clinical specialties. The next sections review broad connections between space and ethics, and then outline the research methods,

Space and ethics

Abstract ethical principles of justice and respect for autonomy involve spatial concepts and metaphors, which sometimes become physical realities in clinical care, for example, 'sharing the cake', 'drawing or crossing the line' and 'invading' personal privacy. . Distributive justice can be visualised as allocating equal, larger or smaller portions of the whole available entity. Respect for autonomy and privacy rights involves drawing an imaginary line around the person, a boundary to keep out unwanted intruders and to guard the space within which the person can think and act freely. The views we hold are characterised in terms of their distance from or proximity to socially acceptable moral norms.

It is partly ironic that Kant's disembodied concept of the inviolable autonomy of the (supposedly) independent eighteenth century property owning man is now applied to helplessly dependent twenty-first century patients on invasive life support machines. At the same time feminist, communitarian and postmodern ethics^{10 11 12 13} challenge Kant's respect for inviolable personal space by considering how everyone is interdependent, and inevitably subjected to (invaded by) numerous social influences. This implies that personal boundaries, if they can or should exist at all, are permeable, shifting, even illusory. An interesting question therefore arises as to whether any privacy or autonomy rights can be relevant or feasible in relation to the most extremely dependent people, such as babies and intensive care patients.

Yet even when autonomy rights are dismissed so that personal space is implicitly reduced to vanishing point, eventually, innermost barriers tend to be accepted: those, for example, that prohibit arbitrary imprisonment, torture or murder and that threaten to destroy the person. From the perspective of ultimate dangers, the more vulnerable the patient, the more invasive and

painful the treatment, and the more essential the 'imprisonment' within the intensive care unit and tangled equipment, then the greater the need may become to protect and respect any vestiges of autonomy as far as possible.

Respecting personal autonomy includes: protecting physical and mental safety, privacy, integrity and reputation; negotiating, listening, explaining and requesting consent when it seems necessary to invade personal boundaries; making space for patients' known views within consideration of matters and decisions that affect them; ensuring fair distribution of resources. The following sections review how these kinds of respect relate to concepts of space in the care of premature and very ill or impaired babies. This respect is validated by the United Nations 1989 Convention on the Rights of the Child (UNCRC).¹⁴ The Convention's 54 articles apply from birth to 'every member of the human family'. A Convention is the strongest form of international treaty, and the UNCRC is by far the most widely agreed and spatially influential one, ratified by 192 governments, all except the United States and Somalia. The Convention emphasises that states and their employees should encourage and support parents' loving care for their children within the family, as far as possible.

Research methods

The study had the approval of the four local research ethics committees and also the consent of practitioners and parents. The 80 babies were a purposive sample selected for a range of ethnic and socio-economic backgrounds and with varied potential or confirmed neuro-developmental problems. A multi-disciplinary advisory group that included parents met six times to discuss at some length the ethical questions raised by the project.

The qualitative analysis involved rereading interview transcripts and observation notes and, for this paper, marking references to space, its ethical significance, and how space was discussed, managed and experienced in the units. Examples and quotations are given to illustrate key concerns in the four NICUs. The analysis is not a statistical measuring of types of views about space, or a generalisable summary of concerns ordered by the frequency with which they were expressed. Some of the most revealing insights might rarely be heard. Instead of asking quantitative questions 'How many?' this paper asks qualitative ones: 'What kinds of meanings, implications and deeper patterns are involved?'

Respect and space, symbolic and practical ethics

Opening and closing access.

Hospitals have changed greatly over the past 30 years. Rooms in maternity wards once spaces for mothers and babies now contain filing cabinets and administrators. 'Swipe' doors opened by plastic cards close off large sections of the wards to all but the staff, and entry is controlled by remote switches worked by staff who observe would-be visitors on closed circuit television screens. These spatial changes crucially affect family life in NICUs. Mothers are sent home within hours or a few days of the birth even when it is clear that

their baby will be in hospital for weeks or maybe months, and there are rarely spaces for them to stay for long in the hospital. During interviews, parents frequently described the pain of leaving their baby behind when they travel home, sometimes long distances, feeling 'as if a kind of umbilical cord is being stretched to breaking point'.

Parents have less access to senior staff who work mainly beyond the swipe doors that restrict parents' access to their babies as much as general visitors' access. A father described to me the not unusual experience for parents of walking up to the NICU with his wife the day after her caesarean section, when no porter or wheelchair was available, very eager and anxious before the first meeting with their baby. 'We kept pressing the buzzer [at the entrance door] but no one answered. We had to wait about 15 minutes and there was nowhere for her to sit down.' The receptionist walked by and he turned to describe to her how their first entrance had been barred. 'But that is so good,' she interrupted him, 'You know your baby is safe here.'

The receptionist implied an ethics in which sick babies belong primarily to the clinical not the family space, and that rational parents accept and trust in this priority with all the accompanying and seemingly inevitable barriers and distancing. In contrast, the parents' urgent ethics of care meant they needed proximity, sitting by the incubator, touching and stroking and, if possible, holding the baby in skin-to-skin contact, the baby tucked inside the parent's shirt sharing personal space. The risk of a baby being kidnapped from an NICU seems slight, when they are guarded by many staff and often connected to many tubes, so that it is questionable whether the swipe doors are installed to protect the babies or the staff. The doors guard clinical control over the NICU, and reduce the risk of disruption and of the staff being blamed if the 'wrong' people move into the unit or out of it. The system offers false assurance when uninvited people can easily slip in or leave with the permitted ones.

NICU layout and design

The design of each NICU could express and reinforce the quality of the relationships between clinical staff and families. Intensive care staff work under such pressure that they have to be quite a tightly united team, which makes it harder for them to cope with the constant flow of relative strangers, the families, in and out of the NICUs, partly justifying the use of swipe cards. However, some units and clinical teams succeed in being far more accommodating and welcoming than others. In an example of a welcoming unit, the clinical areas and the cosy sitting room used by all staff for tea and meal breaks (seeming to encourage inter-professional contacts) were clustered around a small reception area. The staff valued the receptionist's confident and kind manner. In another unit where parents frequently mentioned feeling excluded, the clinical areas were separated along the corridors, doctors but few nurses used a formal sitting room outside the unit, and links to the remote entrance were often left unstaffed. The receptionist was unsympathetic. 'What's their problem?' she asked, during a conversation about distressed parents.

The use of space could signify status and respect. Some NICUs displayed welcome notices in several languages. In a less welcoming one, staff used the large main doors that had notices stating 'NO ENTRY FOR PARENTS,

use the side door.’ Institutions have many overt and covert rules linked to space about who may go where and when they may do so. Some rules were firmly advertised: ‘wash your hands here before entering the nursery’. Others, such as when parents might touch or pick up their baby, or move a chair to the cot side, were often unspoken and varied between different nurses, leaving many parents feeling uncertain and timid. The value set by the clinical team on parenting care for babies was clearly denoted by the amount and quality of space that parents could use. Features in welcoming units included: parents’ double bedrooms; pleasant and sufficient spaces for expressing breast milk; a family sitting room and kitchen with fridge, kettle and microwave stocked with fresh food daily; open access for parents to most parts of the NICU, and an adjacent transitional ward where mothers and babies who needed extra care and observation stayed together. To respect and encourage intimate family care, there were screened alcoves, and big easy chairs in corners or turned to the wall so that parents could relax and evade the constant gaze of passing strangers. In some units, twins and triplets shared one large cot, as they had recently shared the womb. This could double or treble the amount of time that parents spent close to each baby, and appeared to be liked by the babies who wriggled towards each other. After surgery, a difficult labour, or time spent being very ill in intensive care themselves, mothers appreciated easy chairs by the incubators or cots, and nearby kitchens and toilets to reduce painful tiring journeys. These features are summarised from different units, but when they were all missing it was harder for the staff to welcome and support parents however much individual nurses made great efforts to do so; structures in the units affected professional practice.

Family friendly units

NICUs are high technology scientific laboratories and also nurseries, and there are tensions between their complementary but disparate purposes. Some NICUs had reassuring touches, such as nursery pictures and fabrics, mobiles and photographs of babies. One mother considered that there could be:

more cards from people who got better, more sort of feedback from parents being evident in the unit, also to try and break down again that sort of industrial complex sort of feel that you’re in a factory...those little things you hang... you sort of grab hold of as a parent, you know, when you’re thinking... oh, my baby’s never going to get better and you see this article about this baby that was... got better and then you see nice cards of people who have left and it makes you feel there is a light at the end of the tunnel, other people have got through this...

Some units banned nursery fittings as unhygienic or vetoed by the Private Funding Initiative (PFI) firm that part-funded the building and also managed some services in new NICUs. Later the staff were able to display photographs of former patients, starting with those born before 25 weeks gestation, each set of pictures showing an older gestation birth group along the corridor, and parents said how encouraging they found the series, a kind of journey of hope. Monitors and other life-sustaining equipment surround the incubators,

sometimes set as discretely as possible against the wall, but in some units positioned to leave little room for parents' chairs. This can send, often inadvertently, a powerful implicit message that parents are not particularly regarded as welcome, essential and integral contributors to their baby's wellbeing. This layout restricted nurses who wanted to welcome parents, and they would say that each incubator needed the space allowed for each adult patient and not the much smaller space allocated for babies. Whereas one NICU will keep the large charts for the babies' daily records around a central area, others place them on big trolleys in front of each incubator, again limiting parents' access.

The theme of how much the clinical care either edges out or else accommodates the parenting care continues from intensive areas into the high dependency and special care areas. Babies move through these rooms as they grow stronger. New policies about managed networks encourage referral of babies to different neonatal units for intensive, high dependency and special care, a cost-effective use of resources and expertise. However this geographical spreading out of clinical spaces can overlook how the social and emotional cohesion that develops slowly within units between staff and parents could be broken and have to be re-established two, three or more times for each baby, with the problems that these breaks could pose.

In some NICUs and many local special care baby units, nursery nurses manage special care areas primarily as calm cosy nurseries, and concentrate with the parents on promoting the babies' comfort. In other NICUs, all nurses follow more intensive care models. Babies seem to remain longer in incubators and to be left to cry because nurses are busier with routines when parents' access is restricted, explicitly when parents are asked to leave during rounds, implicitly when they are not made to feel welcome and included. One special care room had large wide tables filling the central area, occasionally used by staff doing paper work, while babies and parents were squeezed around the sides, with upright chairs that were 'torture when trying to breastfeed' a mother commented. This layout and furnishing signified how clinical care was assumed to predominate over family care. Here, a mother wanted more

consideration of creating a sort of nurturing stimulating environment for the babies, you know, there's no toys, there's no mobiles, there's no music, there's no soft area where the babies can get out and play...no comfortable chairs and there's no cushions, there's no space...[Instead of] preparing people for... the babies and the parents, for a home environment is still much too clinical and much too sort of industrial [like] a prison, you know, you sit on one little chair, you know, squeezed up next to your cot...

The use of space symbolises and reinforces the neonatal teams' general priorities and how these affect the ethos of the unit.

The use, rather than the amount, of space influenced how practitioners shared responsibilities with the parents. Parents were much involved in the smallest NICU. However, in some bigger units, large rooms were used for storing surplus equipment or for researchers or, in one new PFI unit, were left empty. When this NICU opened, the staff were disappointed that the new

clinical area was smaller than the old one. The four parents' bedrooms were reduced to two, and parents found these stuffy and noisy, without proper windows. Many parents refused to stay in them, or to make the usual final stay there with their baby during the night before discharge. Parents found their sitting room too remote and uncomfortable, instead they used a large and almost empty entrance area that lacked comfort, privacy and windows, and posed an ironic contrast to the cramped clinical areas. The area contained only some chairs and lockers, a few with broken doors, which did not imply that the management were able and willing to protect parents' valuables.

Parents can seldom assess clinical knowledge and skill, and so their trust in clinical staff is influenced by clues about matters that they can assess, such as kindness, respect and efficiency. The parents' room in the less welcoming NICU had only a broken coffee machine; mothers who wanted to breastfeed were advised not to drink coffee. For other drinks and food, parents had to go to the expensive coffee bars several floors away. There were no water coolers or toilets for parents to use in the clinical area. The room for expressing breast milk was so small, that mothers had to queue, to the stress and discomfort of those using the room and also those waiting to use it. As mentioned, PFI involves private companies 'renting' buildings to the NHS. Companies have cost incentives to supply hospitals that are cheap to build and very expensive to run, and to delay making improvements or repairs to failing services.¹⁵ For example, a senior nurse complained for weeks that the fridge for expressed breast milk did not close properly and she had to keep throwing milk away, to the mothers' great distress. The staff were concerned about vandalism by parents, however, in some NICU senior nurses spent much time on ensuring that items were quickly repaired or replaced. They believed that their concern to ensure that the NICU felt a comfortable and welcoming space helped to reduce theft and damage and to ease parent-staff relationships. The neonatal staff were highly knowledgeable and skilled in all the units, and the appearance of the NICU did not indicate their expertise. However, efforts to make the NICU feel like a friendly caring nursery as well as a highly technical treatment and research centre were greatly appreciated by parents.

Space for 'emotion work'

Acknowledgement of adults' emotional inner space appeared to be linked to practical concerns to make the NICU look and feel as homely as possible however small or shabby the unit might be. In the smallest unit, for example, a consultant tried to move away intensive care equipment from the entrance area, saying how frightening it must look to new parents when they arrived. The ethos of the units was affected by the space and attention allotted to 'emotion work'. In welcoming units, senior doctors and nurses tended to refer during their interviews to the importance of support, as part of neonatal care, to help people to share and relieve their inevitable distress. One NICU had weekly separate groups for staff and for parents run by highly trained counsellors, who also supported individuals, besides a full time senior staff member and training sessions dedicated to the babies' emotional wellbeing. The nurses had further regular support and training team meetings. In another NICU there were no formal sessions. Meetings for nurses had been cancelled for 18 months because 'the budget was overspent'. One nurse offered support

to parents, along with other duties, and referred them if they wished to a psychoanalyst in another department, as if overt distress was an abnormal and personal failing to be contained and treated elsewhere, instead of a typical experience that the staff generally tried to alleviate.

Privacy within a public space

Confidentiality in setting boundaries between public and private was respected in different spatial patterns. In one unit, staff were stopped during ward rounds from recounting family's personal details, such as mental health problems. 'This is not our business.' Parents stayed during the rounds. At a unit where personal details about the family were routinely discussed during rounds, parents were excluded from clinical areas during rounds. Here the nurses also protected privacy and confidentiality by discouraging parents from talking to one another and looking at each other's babies, as if setting invisible barriers around each cot and between families. A mother commented how this distancing, for her, affected the ethos of the unit and her relationships with other parents and with her baby.

You felt that there was some sort of unwritten code that you weren't supposed to interact with people 'cause you were told that you were not allowed to look at anybody else's baby or make any comment about anybody else's baby, which I think is right but nevertheless I think that sort of laid down some kind of sense that you therefore shouldn't interact with anybody and that that would be frowned upon, so everybody kind of kept themselves to themselves very much [until they slowly made contact] but I think that should be encouraged more, actually that is a good thing for parents and for the babies, just sort of create a more sort of convivial atmosphere and more sort of friendly normal, inverted commas, atmosphere. [One day I felt my baby is] never going to get out, I can't take this any more and then we [the two mothers] bumped into each other in the lift and we just started talking and then it was just like this torrent of stuff... bla bla bla bla...and we just were standing in the foyer downstairs and just having this manic conversation...it was really brilliant talking to her, I realised ... when you're in that unit, everything's all bottled up and you feel that you have to be discreet, you have to behave properly...you can't express emotion, it's like you've absolutely got to keep a tap on everything and you realise what a strain that is...I didn't feel like able to sing to her or, you know, anything because you feel that you were disturbing the other parents or you were being embarrassing or, you know...disturb the nurses or something, so it's a very very inhibiting environment.

In combining the laboratory and the nursery, NICUs straddle the public service and the intimate private family space. Some cultures have particularly firm divisions in family behaviour either inside or outside the home, when the demeanour of husband and wife can differ markedly between the two settings. One interviewee, a Muslim interpreter and psychoanalyst with a doctorate in medical anthropology, regretted being expected to translate only the words

and not also 'the culture', as he was often aware of cultural misunderstandings.

The father in the interview is more active and the mother is less, normally in the culture the husband has to speak on behalf of the wife. When I come into the room I do not say hello to the woman, it is very delicate, to say hello or to shake her hand. With the husband I do it easily... [To interviewer] With you, I am looking into your eyes because you are a European woman. In our culture it is really not good to look into the eyes...An older person can look at you, the younger person has to look down and to look up only sometimes. [The NICU staff ask him to speak directly to the mother] They wonder why the husband is there and has to respond to everything. The culture is the threshold. When a father speaks on behalf of his wife that does not mean he does not respect her or listen to her, though people think he doesn't think his wife can understand things, but in fact he has to be responsible, the guard of the family he has to be in that position, but in Western culture it is very difficult to understand that. There is an impression that the husband controls the woman but in fact that is not true. At home you will find he does not control her at home, there you can see another person, the woman is completely different, because that is her territory. She is stronger than her husband but when they are outdoors that's another position, different from indoors.

The account illustrates how, by their behaviour, Muslim families tend to demonstrate how they see NICU as public 'outdoors' and not 'indoors'. The account also shows how the ethics of respect can relate subtly to negotiations over personal and private space.

Baby-led space?

Babies' expressed views and aesthetic preferences

Space also relates to respect for rights in clinical care. The UN Convention enshrines three kinds of children's rights, to protection, provision, and participation or a modified form of adults' autonomy rights. Children's rights to personal *protected* space involve safety from neglect, abuse, discrimination, harm, torture and humiliating or degrading treatment. Babies risk being stigmatised and discriminated against if, for example, private problems within their family are unnecessarily divulged, so that respect for their parents' privacy and reputation can be vital to babies too. *Provision* rights involve access to essential goods, services and amenities. Justice in the allocation of such resources raises hard questions for the staff deciding whether there is a spare cot or incubator to admit a baby into.

However, bioethics is especially concerned with people's rights to respect for their autonomy, integrity and dignity, their views and their negotiated consent. Can any of these rights remotely apply to premature babies? The UNCRC's *participation* rights involve children who are able to form and express their own views having 'the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child'.¹⁶ When do children begin to express views that can be taken seriously?

Paediatricians and psychologists have studied babies' constantly altering mood states, and their expressive face and body 'language', concluding that these can be 'read' for many subtle meanings.^{17 18} Babies are seen as agents. From birth they turn towards the sound of their mother's and father's voices, preferring these to other sounds. Breastfeeding succeeds when the mother responds to her (healthy) baby's 'views' on the appropriate pace and timing of feeds to establish supply to meet the demand. The mother-baby dyad continues in a symbiotic physical continuum after birth,¹⁹ such as when contact between them releases mutually beneficial hormones.²⁰ Simple arrangements can affect their relationship. For example, the mother of a profoundly disabled baby who later died spent months sitting by him and in front of a window. Propped up in his cot and turned towards her, the baby kept his eyes screwed up against the light. In some other units, the window would have a screen or curtain, or a nurse would have helped the mother to find somewhere to sit where her baby could gaze at her.

Longstanding research with term babies has been extended to examine very premature babies' language and agency,²¹ with some similar findings, such as recognition of parents' voices. Premature babies constantly try to organise their personal space, gathering their limbs into a self-comforting and soothing fetal position, hands near the face. When nursed in uterus-like cotton nests they are able to relax and sleep, and so gain energy to breathe independently, to feed, grow and resist infection, whereas if they are left supine, limbs extended, they struggle to get comfortable and, if not prevented by tubes, to wriggle into a containing corner of the cot. We observed nurses who understood babies' physically 'expressed views' and helped them to be in their individually preferred position for sleeping, or feeding or being quietly alert. Nurses who did not understand the babies' body language would lift them from the corner of the cot, which they had wriggled towards, and replace them in the centre of the cot, and the babies would restart their journey searching for comfort.

Beyond personal space, babies' obvious expressions of comfort or distress can influence unit-wide policies.²² Babies clearly prefer quiet dimly lit spaces, and often startle awake and cry at slight noises. Some are more sensitive than others and need to be nursed in quieter areas. Yet many NICUs are very brightly lit and noisy. 'Baby-led' policies avoid overhead strip lights, install noise-absorbing tiles and furnishings, and persuade the adults to work quietly. So far, these NICU are unusual, but they illustrate how ethical respect for babies' expressed views, and for babies as sensitive persons, can help adults to provide more therapeutic clinical spaces.

Babies' personal space

Obviously babies are far from being competent to consent. Yet they can resist and comply and, perhaps, cooperate. Possibly this is a passive unknowing submission although, for example, when they begin to breast or bottle feed, they have to be the most active partner and to learn how to behave beyond instinct. Weak babies struggled to manage to combine breathing with sucking and swallowing with intense concentration. Practitioners often 'negotiated assent' in the sense of checking the baby's mood, talking quietly, soothing and preparing the baby for an intervention and, if the matter could be left,

waiting until the baby awoke or stopped crying and seemed better prepared. These adults left space in their plans and activities to include the baby's ascertainable views and allowed these to influence matters that affected the babies.

Babies appeared to learn to distinguish between painful and tender touching and to respond differently to these. In the view of many nurses and parents and of some doctors, many babies seemed to become less upset, and to calm down sooner after a painful intervention if before, during and afterwards someone soothed and spoke to them gently. Psychoanalysts write of children in their second or third year interpreting painful treatments as callous and terrifying torture unless adults are careful to assure them of their benign intentions.²³ Six-month old babies show elements of reasoning, interpreting and meaning making, such as in their surprise if they see effect preceding the cause.²⁴ The premature babies' responses to adults comforting and calming them may be showing the very beginnings of these kinds of sensations of trust, or dread when they flinched in anticipation of the daily heel prick, and of sensing intent from the adults' tone of voice. Faden suggests that dignity is a meaningless concept.²⁵ However, in their treatment of the babies' bodies and surrounding spaces, the adults could highly respect or disrespect babies' bodily integrity and their dignity, whether dignity is a conferred, an integral or a learned quality. Adults helped babies to be contained, calm and content, or left them to sprawl and cry helplessly. These interactions illustrate practical, embodied and spatial significance of ethical principles.

Discussion

This paper has not reviewed conventional ethical questions about choosing which babies to admit to crowded NICUs or when to withhold treatment, although these questions relate to space. Providing or withholding treatment may also involve inclusion or exclusion, striving to help a baby to survive as a member of human society or else to cross the border and to leave this life as comfortably as possible (preferably in a private well designed area surrounded by the grieving family).

Instead, the paper has concentrated on seemingly minor details, to suggest that these are central to clinical ethics in several ways.

Respect and care are combined through ethical standards of practical embodied clinical work within parameters of physical space. The baby is treated as more than a little piece of biology, but also as a responsive person living in social space with a biography, a family and a partly inviolable integrity. These ethical standards depend on adequate planning, NICU design and resources, staff training and support in understanding and responding to babies' 'body language'.

The design and furnishing of clinical areas convey powerful messages that configure the ethos of the unit. They can endorse or undermine the ethical inclusion of parents as partners with practitioners in providing care and sharing in decision-making. If parents are regularly excluded from the unit, they are less able to be informed and involved in making decisions. The NICU design contains metaphors and symbols that reflect and reinforce underlying values such as practitioners' respect for parents and for babies, balancing scientific with humane care, clinical with parental care, high general standards

with individually tailored care, that tries to resolve the dichotomy of the NICU as laboratory and nursery.

Aesthetic features, such as lighting and noise, bustle or calm, take on a moral status when they affect babies' sleep, energy, health and wellbeing.

Stressed parents value not only access but also the quality of comfortable, soothing, welcoming surroundings.

In one view, anxiety and stress are fragmented and confined into an individual's characteristics and perhaps weaknesses. Alternatively, they are perceived as shared, unit-wide, anticipated responses. The former personal-psychological view then broadens conceptually into the latter shared social-political one, which channels concern into improving care for all, as when noise and lighting are generally subdued.

Newborn babies share in carving out space for themselves at the heart of their new family, for example by their magnetic gaze. Premature and impaired babies in NICUs can find this task much harder initially, besides having to surmount extra barriers of separation, and potentially having to rely on family support more intensively than their healthy siblings. For these reasons the sensitive management of barriers and distancing is part of the adults' ethical responsibility to promote familial ties, from simple acts such as drawing a curtain to protect the baby's gaze from bright light, to large ones of redesigning the unit.

Kant's imperative to treat others as persons, ends in themselves with their own aims and values, can be visualised as attentively taking the other's perspective, adopting the point of view of a baby lying under bright lights, or a mother feeling too stressed to breast feed.

There are ethical choices to be made which sometimes balance risk or security against liberty or autonomy, exclusion against inclusion, learning from babies or denying their immediate preferences. These need to be very carefully thought through. The aim of this paper has been to provide examples to encourage clinicians to consider further ways in which ethics and space intersect, and in which space offers vivid practical and symbolic ways to grasp and apply ethical standards. As in a companion paper on neonatal time,²⁶ it is suggested that space can be flexible rather than inexorable in its quantity, utility and quality, a shared resource to negotiate and open or close to higher ethical standards.

Acknowledgements

I am grateful to the families and neonatal practitioners who helped with the study, to researchers Dr Joanna Hawthorne and Ms Margaret Killen, the project's Advisory Group chaired by Professor Farsides who also gave valuable comments on this paper, the four local research ethics committees for their approval, and the Wellcome Trust Bioethics Programme for funding project no. 066458.

References

- ¹ Alderson P, Ehrich K, Hawthorne J, Killen M, Warren I. *Foretelling Futures: Dilemmas in neonatal neurology*. London: SSRU, Institute of Education, 2004 www.ioe.ac.uk/ssru/projects/neonataalfutures (last accessed 7.11.05)
- ² Department of Health. *Reference Guide to Consent for Examinations or Treatment; Seeking consent: working with children*. London: DH, 2001
- ³ Nursing & Midwifery Council. *Code of Professional Conduct*. London: NMC, 2002
- ⁴ *National Service Framework for Children, Young People and Maternity Services*. London: DH. DfES, 2004
- ⁵ Royal College of Paediatrics and Child Health. *Safeguarding Informed Parental Involvement in Clinical Research Involving Newborn Babies and Infants*. London: RCPCH, 2000
- ⁶ Shenoy S, Archdeacon C, Kotecha S, Elias-Jones A. Current practice for obtaining consent in UK neonatal units. *Bull Med Ethics* 2003; **188**:17-19
- ⁷ British Association of Perinatal Medicine. *Consent in Neonatal Clinical Care: Good practice framework*. 2004. Available to members only
- ⁸ Kennedy I. *Learning from Bristol. Report of the public inquiry into children's heart surgery, 1984-1995*. Cm5207. London: Stationery Office, 2001
- ⁹ Redfern M. *The Royal Liverpool Children's Hospital Inquiry Report*. London: Stationery Office, 2001
- ¹⁰ Bauman Z. *Postmodern Ethics*. Oxford: Blackwell
- ¹¹ Garber M, Hanssen B, Walkowitz R (eds.) *The Turn to Ethics*. London: Routledge, 2000
- ¹² Hand S. (ed.) *The Levinas Reader*. Oxford; Blackwell, 1989
- ¹³ Gilligan C. *In a Different Voice*. Cambridge, MA: Harvard University Press. 1982.
- ¹⁴ United Nations. *Convention on the Rights of the Child*. Geneva: UNESCO, 1989. www.unesco.org (last accessed 7.11.05).
- ¹⁵ Pollock A. *NHS.plc*. London: Verso, 2004
- ¹⁶ United Nations. *Convention on the Rights of the Child*. Geneva; UNESCO, 1989 www.unesco.org (last accessed 7.11.05) Article 12
- ¹⁷ Brazelton TB, Nugent JK. *Neonatal Behavioral Assessment Scale*, 3rd edition. Clinics in Developmental Medicine no. 137. London: MacKeith Press/Cambridge University Press, 1995
- ¹⁸ Murray L, Andrews H. *The Social Baby*. Richmond: Children's Project Publishing, 2000
- ¹⁹ Leidloff J. *The Continuum Concept*. London: Futura, 1976
- ²⁰ Uvnas-Moberg K. Oxytocin may mediate the benefits of positive social interaction and emotions. *Psychoneuroendocrinology* 1998; 32(8):819-35
- ²¹ Als H. *Reading the premature infant*. In Goldson E. (ed.) *Developmental Interventions in the Neonatal Intensive Care Nursery*. New York: Oxford University Press, 1999: 18-85
- ²² Alderson P, Hawthorne J, Killen M. The participation rights of premature babies. *Int Journ Children's Rights* 2005; **13**:31-50
- ²³ Melsak S. Secrecy, privacy, survival, repressive regimes and growing up. *Bulletin of Anna Freud Centre* 1992; 15: 205-24
- ²⁴ Siegal M. *Knowing Children: Experiments in conversation and cognition*. Hove: Lawrence Erlbaum Associates, 1997
- ²⁵ Faden R. Dignity. *BMJ*
- ²⁶ Alderson P. Time in the neonatal unit. Forthcoming.